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## **HCCA Feedback: NHMRC Statement on Consumer & Community Involvement in Health & Medical Research (“the Statement”)**

Thank you for the opportunity to provide feedback on the above Statement.

### Guideline rather than Statement

We propose that the Standard be a NHMRC Guideline as allowed for under the *National Health and Medical Research Council Act 1992 7(1)(a)(iv)* as it relates to “public health research and medical research”<sup>1</sup> and follow the existing Standard for Guidelines. The Guideline would meet Standard 1 to be “relevant and useful for decision-making”<sup>2</sup>.

### Proposed Guideline Purpose

We propose that the purpose of the Guideline is to outline the expectations against which the NHMRC will assess research proposals’ consumer and community involvement in health and medical research.

That is, the Guideline will be NHMRC’s transparent decision-making tool that assessors will use to rate consumer and community involvement in research proposals. In effect it would outline NHMRC’s minimum standards for consumer and community involvement in health and medical research and provide guidance to researchers in writing their proposals. For example, the minimum expectation for consumer and community involvement could be “partnering with researchers” in the carrying out of research, with co-participation, co-design and co-production carrying greater weight in assessments.

### Language and audiences

The above change requires a change of language to “must” and “will” from “can” or “may”. That is, research proposals put to NHMRC must demonstrate how they meet the expectations of the Guideline and decision-makers must use the Guideline in assessing research a proposal’s approach to meaningful consumer and community involvement in the project.

In its current form, the Statement is predominantly addressed to researchers. If consumers, partners, communities and research organisations are to be treated as equal partners then the Statement needs to address all of these audiences equally.

The Statement needs to be accompanied by a Plain Language Summary, a Guide for Consumers and Communities and an Easy Read version.

### **Health Care Consumers’ Association**

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Absence of consumer organisations

Consumer-based organisations are vital partners in supporting consumers in their advocacy and representation roles. Consumer-based organisations can also assist researchers and research organisations in partnering with and accessing consumers. We support the submission made by Health Consumers NSW and NSW Users and AIDS Association, which addresses this issue in detail.

We include below our responses to the survey questions which includes feedback from our members.

Thank you again for the opportunity to provide feedback on the Models.

Yours sincerely



Darlene Cox  
Executive Director  
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<sup>1</sup> <https://www.legislation.gov.au/C2004A04516/latest/text>

<sup>2</sup> <https://www.nhmrc.gov.au/guidelinesforguidelines/standards>



## **Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research – Position Paper Questions**

We are encouraging all interested stakeholders to provide a written submission to the questions in the NHMRC Consumer Statement Review Position Paper via NHMRC's Consultation Hub. These questions will also be discussed in an open forum at Australia-wide workshops in the first half of 2024.

You may enter your responses directly using the online survey. If you provide an email address, you can save your progress and return to the survey as many times as you wish while it is open.

This document has been developed for individuals and organisations who would prefer to prepare their responses offline, for entering on NHMRC's Consultation Hub once complete. It contains the discussion questions in the order that they appear in the online survey.

Please note that none of the questions below are mandatory, and that there is no word or character limit for each question in the online survey. You are welcome to provide a response to as many or as few questions as you wish. You will also be asked some questions about you or your organisation when you complete the online survey.

Please ensure that you have read the Position Paper (available for download on the Overview page of the survey) prior to answering the questions.

### **The current Statement and importance of consumer and community involvement in research**

The current (2016) statement is available for download from NHMRC's website at: <https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research>

- What parts of the current Statement have or have not worked well?

Members noted that there appears to be a disconnect in how institutions, researchers and possibly consumer and community members, respond to what consumer and community involvement entails. This ranges from the planning stages (deciding what to research, and deciding how to do it), conducting the project (Doing it), through to concluding the project (letting people know the results, and knowing what to research next).



The current Statement uses a mix of “can”, “should” and “may” language. There is a need to strengthen the Statement by using language that necessitates its adoption. For example, the Statement should state that it **will** be used in assessing all funding application to the NHMRC and that funding applications **must** include how consumers and communities will be partnered with in the research project or a statement as to why consumers and communities are not being partnered with, which will also be assessed against the Statement.

The Statement must show how NHMRC will use the Statement in its decision-making processes.

The Statement would benefit from an infographic that outlines the relationships between its various sections (Vision, Values, Purpose etc) such as that used in “A Guiding Framework for Consumer and Community Involvement in Health Research at Sydney Health Partners” available at <https://cdn.sydneyhealthpartners.org.au/wp-content/uploads/2023/03/CCI-Framework.pdf>

The Statement also needs to be accompanied by a Quick Guide for all stakeholders, a Plain Language Summary and Easy Read formats to improve its accessibility.

The current Statement does not include the important role of non-government consumer organisations in assisting consumer and community involvement in health and medical research. These non-government organisations need to be reflected in the Statement.

There needs to be clear definitions of key terms in the statement. Health Consumers NSW and Sydney Health Partners developed a Consumer and Community Involvement language guide to support consumers and researchers to understand key terms in Consumer and Community Involvement (see the link below).

<https://cdn.sydneyhealthpartners.org.au/wp-content/uploads/2023/03/CCI-Language-Guide.pdf>

We strongly recommend that the NHMRC use this language guide to define key terms particularly, the difference between participation, involvement and engagement in health and medical research.

The existing Statement refers to levels of consumer involvement in Appendix 3 and other guides on consumer involvement in research in Appendix 4. However no assessment is made of each of these resources. The revised Statement would benefit from referencing Best Practice Guides and Resources.

The Statement would benefit from best practice examples under each of its sections.

- Why is consumer and community involvement in research valuable?

Involving consumers with lived experiences and community organisations that have a wider view of consumers they represent, holds the potential to better target where and how research is conducted.



Research institutions and researchers may need assistance to avoid unintentional bias and outcomes that might not reflect real world lived experiences of the cohort they are trying to assist.

Research must be:

- Relevant
- Meaningful
- Accountable
- Translatable

Consumers and the community have a fundamental right to be actively involved in all health research and throughout the research process. Involving consumers improves the engagement and participation of consumers and the community in health and medical research.

- Why does consumer and community involvement in research matter to you?

See above

Consumers with chronic conditions, with lived experiences, have much to share to aid in the targeting of what research is conducted, how it is conducted, how quickly it is conducted and how the outcomes are communicated.

It is hoped that through this involvement, the outcomes will be delivered with a focus on delivering the results required and in a timelier manner, rather than the research resulting in “further research is required”.

These aspects should then deliver better value for money outcomes for stakeholders from government, research institutions, through to consumers.

### **Value Statement**

A value statement is important as it is a brief, high-level statement that underpins and acknowledges the spirit and purpose of consumer and community involvement in the research cycle. The value statement will help to embed the aspirations of the principles into better practice.

- What overarching values are essential to include in the value statement of the revised Consumer Statement, and why?

The existing Value Statement should include “consumer participation”.

Respect, equity, collaboration, inclusion, diversity, transparency and trust are all appropriate values.



Each of these values/principles should be defined to promote equal partnerships and/or equity between consumers, communities, researchers and researcher organisations.

- The values that underpin the 2016 Statement are ‘shared understanding, respect and commitment.’ How might this be strengthened and improved in the revised Consumer Statement?

The existing Value Statement should include “consumer participation” including of people with lived experience of the health condition being studied, wherever feasible.

In the supporting commentary it uses “encourages” researchers to consider the benefits etc of consumer and community involvement, rather than “requires” involvement.

- Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the revised Consumer Statement?

Yes.

### **Better practice principles for consumer and community involvement in research**

The Position Paper provides some examples of broad principles that could be included in the revised Statement. You are welcome to provide comments on these examples, or on any other principles you would like to see included.

- What do you regard as the most important principles that should be included in the revised Consumer Statement?

The proposed principles are concise and appropriate. Of these “Respect for lived experience and community expertise” stands out as important

Each of the principles require definitions and examples. For example, “involved” and “partnership” both have a range from minimal involvement/partnership through to co-production. The Statement should articulate these ranges and provide a minimum standard for consumer involvement/partnerships.

### **Roles and responsibilities**

The Consumer Statement Review Position Paper provides some examples of roles and responsibilities **of consumers and community members, researchers, research institutions and research funders** that could be included in the revised Statement. You are welcome to provide comments on these examples, or on any other roles and responsibilities you would like to see included.



- What roles and responsibilities for **consumers and community members** should be included in the revised Consumer Statement?

The roles, expectations and responsibilities can be enhanced by:

- substituting “can be involved” to “must involve”;
- more emphasis on the conducting of the projects. At present there are examples of involvement at limited intervals across the project lifespan, resulting in haphazard inputs of consumers and community rather than seeking genuine inputs throughout the process.

The roles and responsibilities through the document appear repetitive in referring to institutions, researchers, consumers and community in each section, rather than narrowing the focus on the cohort covered under the heading. This detracts from the document.

It might be better to have a set of roles & responsibilities that are common to each of the stakeholders and then just list the ones that are unique to each stakeholder.

### **What is missing:**

There should be a recognition of the importance of trauma informed approaches in working with consumers. Consumers can be retraumatized by researchers, particularly if consumers are not actively involved in the early stages of the research process. Involving consumers throughout the research process should reflect trauma informed approaches.

Skills development for consumers is critical: they need training and support to be actively involved in research. This needs to be funded by the NHMRC.

It needs to be recognized that consumers already have a range of skills that can be useful in the research process. This needs to be recognised alongside any training and support that may also be required.

Consumer organisations have not been recognised in the statement. Consumer organisations that work with consumers and represent the interests of consumers in the research process are critical partners and should be recognised in the Statement.

- What roles and responsibilities for **researchers** should be included in the revised Consumer Statement?

Combined professional development needs to ensure payment for participation for consumers.

Consumers involvement needs to be mandated, not “should consider” by researchers.

- Should involvement of consumers and community members be an expectation of research?



Yes

Provide reasons for your response below.

Consumer and community involvement in all aspects of health and medical research should be a requirement, not just an expectation. This is necessary to ensure that real world experiences are taken into account and ensure research is relevant and meaningful to consumers.

Consumers and the community have a right to be active partners in all health and medical research. The involvement and engagement of consumers and the community in research improves the health research that is undertaken and health outcomes across communities. It also supports the participation of consumers, patients, people with living experience in all health research which improves health outcomes.

- Is there an ethical imperative to involve consumers and community representatives in research?

Yes

Provide reasons for your response below.

This is necessary to ensure that real world experiences are taken into account and ensure research is relevant and meaningful to consumers.

Consumers and the community have a right to be involved in research, it improves the kind of health research undertaken which supports the recruitment of consumers, people with lived and living experience and patients to be participants in health research

- What roles and responsibilities for **research institutions** should be included in the revised Consumer Statement?

While the aspect of education and training, at least for institution participants, may be achievable, it is unclear, or rather purely aspirational as to how consumers can achieve this. Those with lived experiences, CALD members etc are often already financially stretched due to their chronic condition, or age etc.

Requires more than just a commitment by research institutions to involve consumers & communities in health & medical research. Research institutions should have Memoranda of Understanding with consumer organisations and policies and procedures for the involvement of consumers. These should be co-written with consumers.



- What roles and responsibilities for **research funders** should be included in the revised Consumer Statement?

The examples provided are well covered other than that research funders “can” involve consumers. It should be “must” or at least “should” involve consumers. This would lead to better outcomes for the cohort it is aiming to achieve benefits for.

- Should funders of research mandate the involvement of consumer and community representatives in the research they fund?

Yes

Provide reasons for your response below.

Consumers can be involved at any stage of the research process including in discovery science. There needs to be further training for researchers and consumers to be actively involved in any kinds of health research.

### **Implementing the revised Statement**

The revised Statement is intended to be a high-level, overarching document that does not focus on issues related to implementation of consumer and community involvement in health and medical research. However, we acknowledge that you may like to share your views on how the revised Statement may be implemented. Responses to the questions on this page may be used to develop implementation guidance once the revised Statement is published.

- How should researchers involve consumers and community representatives in their research?

The Statement deals with many aspects quite well, with the following exceptions:

- Elements for processes are contained in appendices rather than the main body of the document which creates the risk of omission.
- Inclusion of Appendix 3 into the main body of the document is essential.

The contents of Appendix 3 has gaps:



- In “Doing it” it doesn’t actually detail the involvement processes during the research project.
  - It should deal with the remuneration aspects of involving consumers.
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- o What issues should be considered once the revised Consumer Statement has been finalised and published?

Before the Statement is finalised consideration needs to be given to the proposal to remove “putting the statement into practice”. This creates significant risk to consumer and community groups.

The revised DRAFT Statement needs to be widely disseminated for comment and feedback.

The involvement of consumers and the community in health and medical research requires the funding of infrastructure to support the **capability** and **capacity** of consumers to be involved in health and medical research. Consumer organisations approached to be research partners for NHMRC grants are often asked to provide in-kind support for research grants which is not financially sustainable. Consumer organisations should be funded to be research partners in NHMRC grant applications.

*No attention to capacity building*

The implementation guide for the CCI Statement should be improved and there needs to be a central repository where resources, tools and templates are shared. This includes tools and templates for researchers and for consumers. It could also include an accreditation process for researchers and consumers in CCI in research. Following this there could be an app or website developed with consumers where consumers can register their interest for being involved in research which is actively managed by a consumer organisation (this would be different from existing registers, such as *Join Us*, for consumers who are interested in becoming research participants).

*No recognition of barriers to Consumer and Community Engagement imposed by national research infrastructure*

The current NHMRC sapphire system is designed for researchers. The NHMRC requires consumers or consumer organisations who are research partners to register their details on the NHRMC Sapphire system. This system is not consumer friendly and is purely designed for researchers rather than consumers. This system needs to be reviewed in partnership with consumers and consumer organisations to ensure that it is accessible for consumers and consumer researchers.

There needs to be consideration for how the NHMRC review the track record of consumers in research which should be a separate process from researchers. Many



consumers with lived experience become involved in research through their lived experience and may have many years of experience as a consumer representative but limited publications. The current NHMRC system disadvantages consumers.

Consumer organisations need additional funding to build a pool of consumers trained in understanding health research. NHRMC should fund consumer organisations to build and develop infrastructure to support the capacity of consumers to be involved in research.

### **Other issues for consideration**

The NHMRC could fund online tutorials for consumers and researchers on the NHMRC grants process.

NHMRC applications should be assessed and ranked in terms of the extent of consumer involvement in research.

Along with the strategic plan/roadmap, develop a plan to measure what good Consumer and Community Involvement looks like from a consumer perspective in NHMRC grants.

A Plain Language Summary and Easy Read Guide should accompany the final Statement. Graphical presentation should be considered throughout with Key Points Summaries at the start of each section.